“ADDING DAYS TO A LIFE, OR LIFE TO THE DAYS”

PARENTS AND PHYSICIANS’ PERSPECTIVES ON DECISION-MAKING IN A DUTCH INTERVIEW STUDY.

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*none.*

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*Me:* “So, is it okay if I use your drawing for my presentation?”

*Niece (5 y.o.)*: “Yes, if the people like it they can hang it in a frame on their walls, but they should not.. like... sell it for money.”

*Me:* “I’ll make sure they know that.”
Research & Methods

In-depth interviews + qualitative analysis

Parents of 46 children

33 physicians

Parents of 46 children

In-depth interviews + qualitative analysis

1-12 years old

With life-threatening conditions

Died after a medical trajectory (<5)

Parents of 46 children

Metabolic
Neurology
Muscular
Oncology; Neuro
Oncology
Cardiology
Research & Methods

In-depth interviews + qualitative analysis

- General practitioners
- General paediatricians
- Hospice-based paediatricians
- Paediatricians sp. oncology
- Paediatricians sp. neurology
- Paediatricians sp. cardiology
- Paediatricians sp. metabolic conditions
- Paediatricians sp. neuromuscular conditions
- Paediatricians sp. Congenital disorders/intellectual disability physicians
- Paediatricians sp. immunology
- ICU Paediatricians

33 physicians
How do parents and physicians talk about the crucial decisions for children with an uncertain future?
Major themes

“Should we do everything that can be done?”

proportionality

1 NVK. Richtlijn Palliatieve Zorg voor Kinderen [Guideline Palliative Care for Children]. Available at: http://richtlijnendatabase.nl/richtlijn/palliatieve_zorg_voor_kinderen
"Shared decision-making!"

(But what does that mean?)
Decision-making: end-of-life decision-making?
Major themes

- Proportionality
- Shared Decision-making?
- Focus on end-of-life decisions.
Not every decision is the same.

- Treatment-initiated
- Deterioration-initiated
- Long term decisions
Mother of girl (3)

“With the treatment options, and the impact of radiation therapy, the crucial decision we had to make was:

Do we add days to her life, or life to her days?
“And one day [...] I was in the pool with her, and it suddenly hit me. I thought: This is what you want, just moments to enjoy with us. And the radiation-therapy is only going to take that away from you. So that was when I knew what to do.
“What I can provide is the medical framework, the medical implications and limitations in which we can work. But what it means for their life, that is up to them”
# Treatment- initiated decisions: Take home message #1

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<th>Proportionality</th>
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<td>Should we always do everything? Not about ignoring best interest of the child.</td>
<td>The physician takes a step back, seeing the decision on quality-of-life a private decision.</td>
<td>The decisions are life-oriented, even in life-limiting decisions. Are we using the right terminology?</td>
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"We make these decisions, such as DNR, or no ICU admission in our medical team. And after that we inform the parents.

"And can you describe what these decisions are about?

Sometimes about chance of survival, but with children with metabolic conditions also often about what their life might be after a period in the ICU might be like.
It is difficult to let a parent make a decision about for example ICU-admission, if they have no idea about what it might do to their child.

So sometimes, we follow the parents wishes the first time, so they know what it is like, and we can decide together a second time.”
“I discussed the option of a DNR, but the parents are not ready for that yet. So we are postponing that decision until another pneumonia.”

“Over and over again they Try to push us towards stopping the treatment. It makes me so angry [...] Because we see so much to joy in the life of our daughter.”
"I discussed the option of a DNR, but the parents are not ready for that yet. So we are postponing that decision until another pneumonia or something alike.

Over and over again they try to push us towards stopping treatment. It makes me so angry. Because we see so much joy in the life of our daughter."
The balance of quality of life vs impact of treatment are still often at the core of these decisions. Despite the fact that quality-of-life plays a major role, Decisions are much more physician-oriented. Physicians see these decisions as end-of-life decisions, but parents do not always see it that way. (tunnelvision)
Long term decisions

When treatment or illness forces us to make decisions, communication about it is usually quite open.

But what if these moments do not arise?
Her body is so strong, she might live for years, decades.

So looking back at that pneumonia, I wonder (cries) if we have missed an opportunity, to let her go. Because right now, even though she suffers, there is no option.
Long term decisions

The physicians are going out of their way to provide us with medical possibilities ....

Except for helping us with the actual question: should we really keep going on with all these interventions?
Long term decisions: Take home message #3

We should talk about proportionality and shared-decision making here...

But when there is no direct need to treatment decisions, parent feel often left alone with their questions regarding the proportionality of the treatment.
Discussion

Should we reevaluate the use of the terminology “end-of-life-decisions?

- decisions focus on (quality of) life
- Risk of tunnel vision

- We all advocate shared decision-making... but we don’t always mean the same thing.

- It takes brave physicians and parents to communicate about decision-making when there is no direct need. How can we help the ones that are not so brave?